Study L-4003 October 5, 2000

Third Supplement to Memorandum 2000-62

Family Consent in Health Care Decisionmaking for Adults (Materials Submitted for October 2000 Meeting)

The attached materials were submitted to the Commission for the October 5, 2000, meeting, concerning family consent in health care decisionmaking:

Exhibit p

- 2. Dr. Michael Siegel, Chair, Council on Ethical Affairs, California Medical Association, San Francisco (Oct. 5, 2000) 4

Respectfully submitted,

Stan Ulrich Assistant Executive Secretary Kaiser Permanente Medical Care Program 1950 Franklin Street Oakland, California 94612-2998



October 5, 2000

Stan Ulrich Assistant Executive Secretary California Law Revision Commission 4000 Middlefield Road, Room D-1 Palo Alto, California 94303-4739

Re: Family Consent in Health Care Decision-making for Adults; Commission Memorandum 2000-62; October 5, 2000 Meeting in San Francisco

Dear Stan:

I would like to submit comments in response to the Commission's draft proposal as attached to the above-referenced memorandum concerning family consent for adults without decision-making capacity.

I appreciate the Commission's work to try and identify a means of determining who should make medical decisions for an incapacitated adult who has made no prior arrangements. While I would welcome some clarity as to how to proceed in this frequently encountered clinical situation, I wonder if language can be found that is both adequately flexible for the varieties of patients, families and situations we encounter while providing sufficient guidance in complex situations. My greatest concern is that any attempt to legislate this procedure will create more foreseeable and unforeseeable problems than resolution to the current clinical challenges we face.

I cannot express strongly enough my opposition to a rigid hierarchy as proposed. As Mr. Carlson says, the hierarchy you have listed may be the appropriate hierarchy in a majority of situations. However, acknowledging that as a general guide in society and codifying it in law are two very different things. Not stating the hierarchy does not prohibit the ability of the spouse or the children or the parents to be designated as surrogates in that order when appropriate. However, a statutory listing, even with the provisions you have allowed for challenging it, will become the rule in clinical practice. It will become unduly burdensome for families to alter that hierarchy and will lead to the subjugation of patient preference to an arbitrary listing of next of kin.

In your current draft, you propose giving a "super priority" to a surrogate chosen by family consensus or unanimity of the involved family. If there were such unanimity, I can't imagine any physician, ethics committee or any others that would not give complete authority to such an individual with or without statutory guidance. In such a non-conflicted situation, as an ethics committee chair, I would be grateful for such easy

resolution. Given that, I am still concerned about the development of statutory language for such a straightforward situation.

In this type of ideal situation where there is no family conflict, conflict may be precipitated when the family is asked to identify one decision-maker from among the group. While the group may have consensus on what the patient would want and what medical decisions are appropriate, a variety of perverse dynamics may be needlessly introduced into the process by requiring the group to identify one decision-maker. Claims of privilege and authority attendant to the role could jeopardize the consensus that had previously been unproblematic. I have seen these dynamics created by the comparatively innocuous request that the family choose one member to check in with nursing staff for regular updates on the patient's condition and communicate that information to other family members in order to minimize telephone interruptions for the nurse.

I think we are also expecting families to undertake a selection process that could prove unduly burdensome in a crisis situation. I don't think the ideal you describe, that "all viewpoints will be heard and considered and the substantive surrogate qualification standards will have been applied by the family members in making the selection" can be reasonably undertaken by a family in a crisis situation when the selection needs to be made quickly and the stakes are high. I also agree with your assessment of family processes that can be easily corrupted by a dominant personality. I am concerned that we not write legislation that proposes an ideal standard that is unrealistic in the clinical context. I would also hesitate to ask a non-conflicted family to spend their time on this type of deliberation rather than on considering the medical situation and needed decisions with which they are more reasonably concerned.

The consensus surrogate does give the family a mechanism for overcoming the rigid hierarchy proposed in 4712 when there is agreement, but such authority is limited by the caveat of unanimity. For example, there might be family consensus of the children, parents, brothers and sisters and close friends of the patient that the abusive spouse should not be the decision-maker for a patient. But if that spouse objects, then that consensus is nullified. While you attempt to address how to proceed in such a situation in Sections 4713 and 4713.5, I find the processes identified to be somewhat unrealistic. If there is no conflict, then the statutory language is not needed. If there is conflict, then statutory language is not going to help families, who are confronted with a very stressful situation, to work through long-standing conflicts. I cannot agree more with Ms Eaton's comments that "What seems to work best is when we take the time to assess how the particular family in question operates and attempt to obtain decisions within that structure."

I have some concerns about section 4713 where you describe the qualifications of the surrogate. In general, I agree, it is most useful for the surrogate to be physically present and available to visit the patient and consult with health care providers. I am concerned about making it a requirement, however, since appropriate decisions could be made by an individual at some distance. The current electronic capacities for communication can

effectively overcome geography to such an extent that I would not like to see it put into statutory law that the surrogate must be physically present.

I do not see that the proposed changes would provide substantial benefit or relief from the clinical complexities we currently face when the patient has not identified a surrogate. I also do not believe that they would provide any protection of patient interests and have great concern that they could, in fact, compromise patient interests in service to the interests of others. I would support the proposed clarification of capacity as you have suggested in 4609 and I appreciate the clarification of the status of an oral designation of a surrogate when there is an existing written designation of an agent.

I would like some clarification as to the precedence of oral directives or instructions that are in conflict with prior or even later written instructions or that are in conflict with other oral instructions. For example, a patient recently told her physician that she "did not want to be a vegetable or kept alive on machines" while telling her agent "don't let them give up on me, I want to be coded 6 times." When she was in a persistent vegetative state two months after her first cardiac arrest, her agent continued to insist that she should be coded 5 more times even though she had metastatic cancer and was dependent on several technologies.

I would also ask the Commission to reconsider the section that makes a a health care agent liable for the costs of disposition of the body. When I inform people of these costs when teaching about advance directives, people are universally appalled that the agent should be confronted with such a responsibility and identify it as a barrier to appointing an agent. I am also unclear if such responsibility would devolve onto a surrogate appointed orally.

Thank you for the opportunity to comment on these issues. Please feel free to call me to discuss any of these points further.

Sincerely,

Theresa Drought, PhD, RN

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From: Michael Siegel

Date: Thu, 05 Oct 2000 12:37:16 -0700

To: <commission@clrc.ca.gov>

Subject: 10/5/00

Dear Mr. Ulrich,

Forgive me for using the informality of email; I had hoped to save some time. I was unaware of the exact timetable the Commission would observe based on your 10/5 agenda. Regrettably, I was unable to remain until the PM session.

If it is not too late, I would like to ask that these few issues be considered, mainly with respect to Mr. Carlson's comments on Memorandum 2000-62 as laid out in the supplement.

First, I thank the staff for its good work in attempting a moderate compromise. I would point out, reiterate more likely, that a surrogate arrived at by consensus of available family and friends is hardly likely to be anywhere BUT at the head of a list of possible candidates, without the benefit of statutory support. Our problem is much the opposite: the absence of a surrogate or competing surrogates.

Section 4713.5(c): If this provision concerning the absence of a surrogate or competing surrogates, is omitted, someone who has the "sophistication, resources, time and determination,... can petition the court" Is a court solution what we are hoping to achieve, or avoid? In crises, no one will fit the above description. My own experience concerns situations where the Public Guardian in our county will issue DNR consent for an unrepresented, incapacitated patient, but will hardly do so with respect to withholding or withdrawing treatment. The court process is too cumbersome and time consuming. Ditto when there is a contest between spokespersons.

I personally believe in the effectiveness of multi-disciplinary Bioethics Committees in resolving most of these matters. As yet, composition of these committees is I expect non-uniform in California Hospitals; perhaps this is something which should be legally mandated to ensure that no one physician, or physician group will have ultimate say.

Section 4713.5(b): Mr. Carlson's statement that physicians can refuse to comply with an unable or inappropriate surrogate's decisions rather than rejecting the surrogate's authority fails to consider how the patient's surrogate will be replaced, in a timely fashion, by someone more suitable. What mechanism is prescribed?

How could a physician, or any other health professional "opt out" of a patient's care knowing that the surrogate is failing to comply with a patient's advance directive or to act in the patient's best interest? Certainly, for the surrogate to do so is illegal per the HCDL; is it not also illegal and immoral to place one's patients at the mercy of surrogates who neglect them in failing to make decisions, or abuse them in making decisions to which the patients would be opposed?

Thank you for time and consideration.

Sincerely,

Michael Siegel, MD Chair, Council on Ethical Affairs California Medical Association PO Box 7690 San Francisco, CA94120-7690